

Unlocking the Potential of Interoperable, Linked, Low-latency National Health Data in England to Protect Vulnerable Patients while Safeguarding their Privacy: A Brave New World

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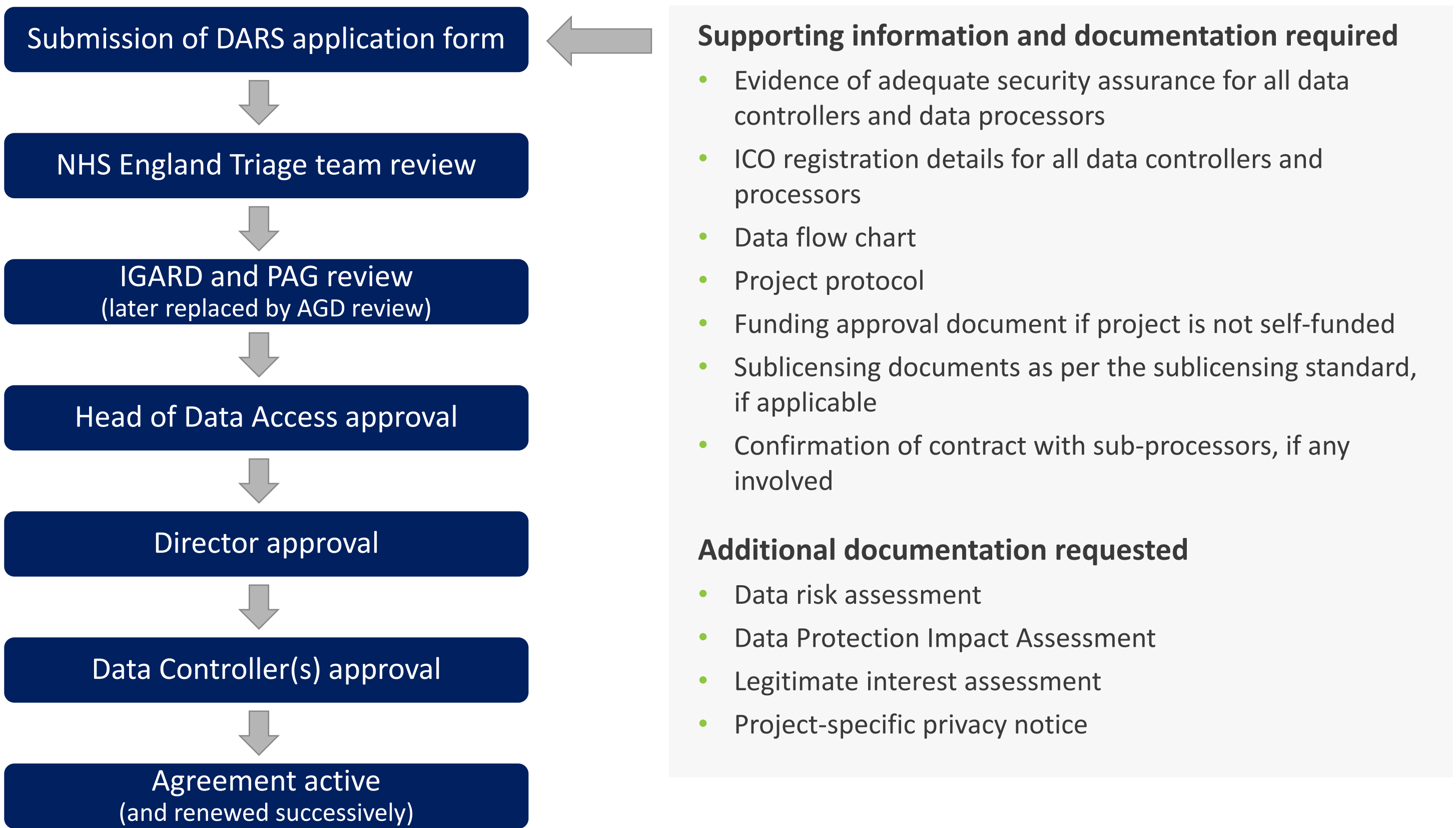
Background and Objective

- National Health Service (NHS) England routinely collects national healthcare data, which is provisioned for research for approved investigators to access for permitted projects. Despite this wealth of data, the timely, secure, and continuous access during and after the COVID-19 pandemic challenged the traditional data sharing model.
- Evidera and AstraZeneca piloted NHS England's Secure Data Environment (SDE), part of the NHS Research SDE Network, for their burden of COVID-19 study (INvestigation of cOvid-19 Risk among iMmunocompromised populations [INFORM], ISRCTN53375662).
- We aim to present this unique public-private collaboration on data access as a case study.

Data Application Process

- Applicants are required to provide details and substantiate compliance with all normative provisions and assurances pertaining to information technology security, data protection, and risk management (Figure 1).
- Access to primary care data from the General Practice Extraction Service (GPES) had never been granted to private entities, so additional scrutiny and safeguards were exacted for this application.
- Thus, the INFORM study became a great fit to pilot NHS's new SDE.

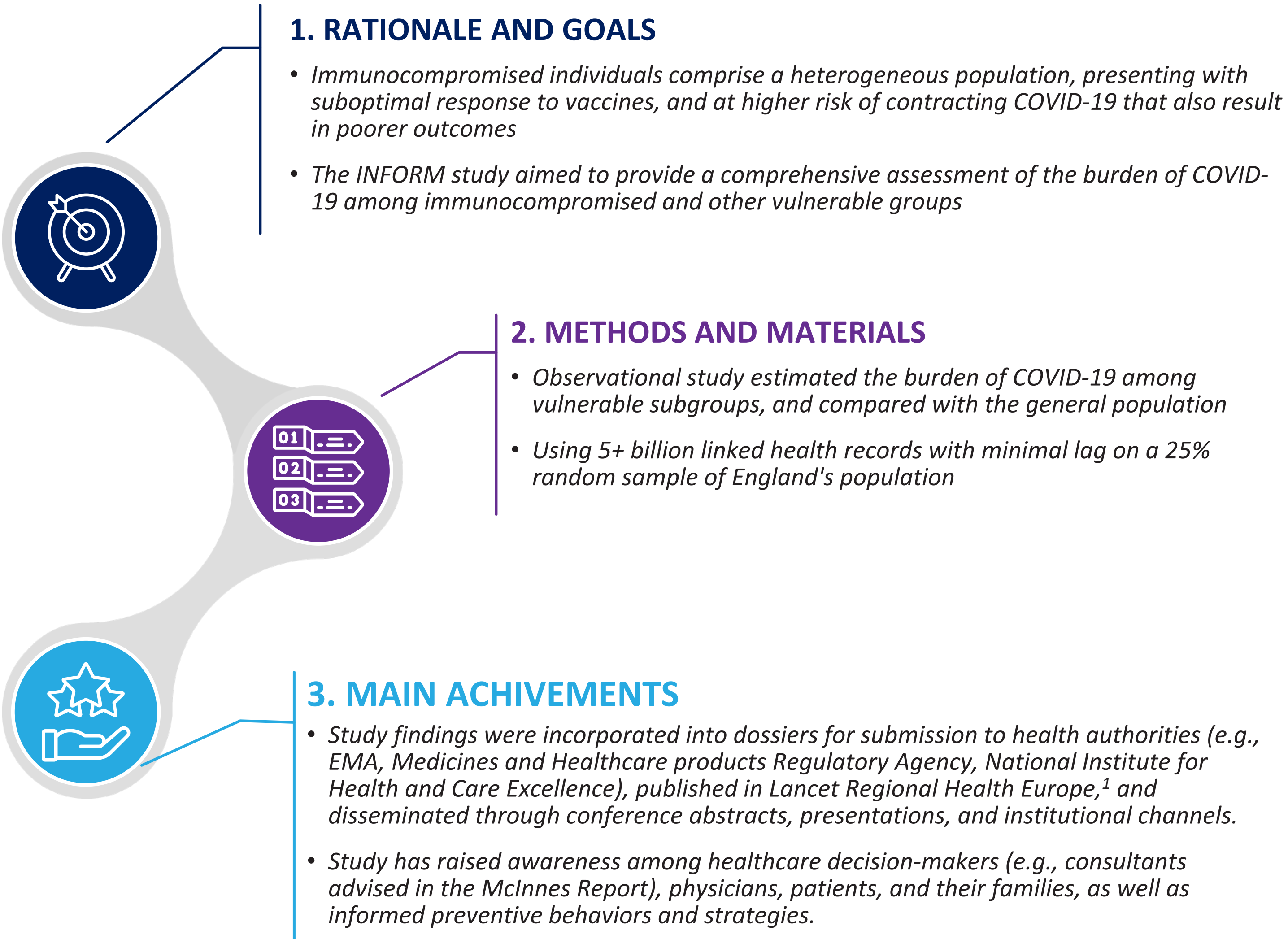
Figure 1. Overview of Data Application Process



Abbreviations: AGD = Advisory Group for Data; DARS = Data Access Request Service; ICO = Information Commissioner's Office; IGARD = Independent Group Advising on the Release of Data; NHS = National Health Service; PAG = Profession Advisory Group

Overview of INFORM Study

Figure 2. Overview of the INFORM Study



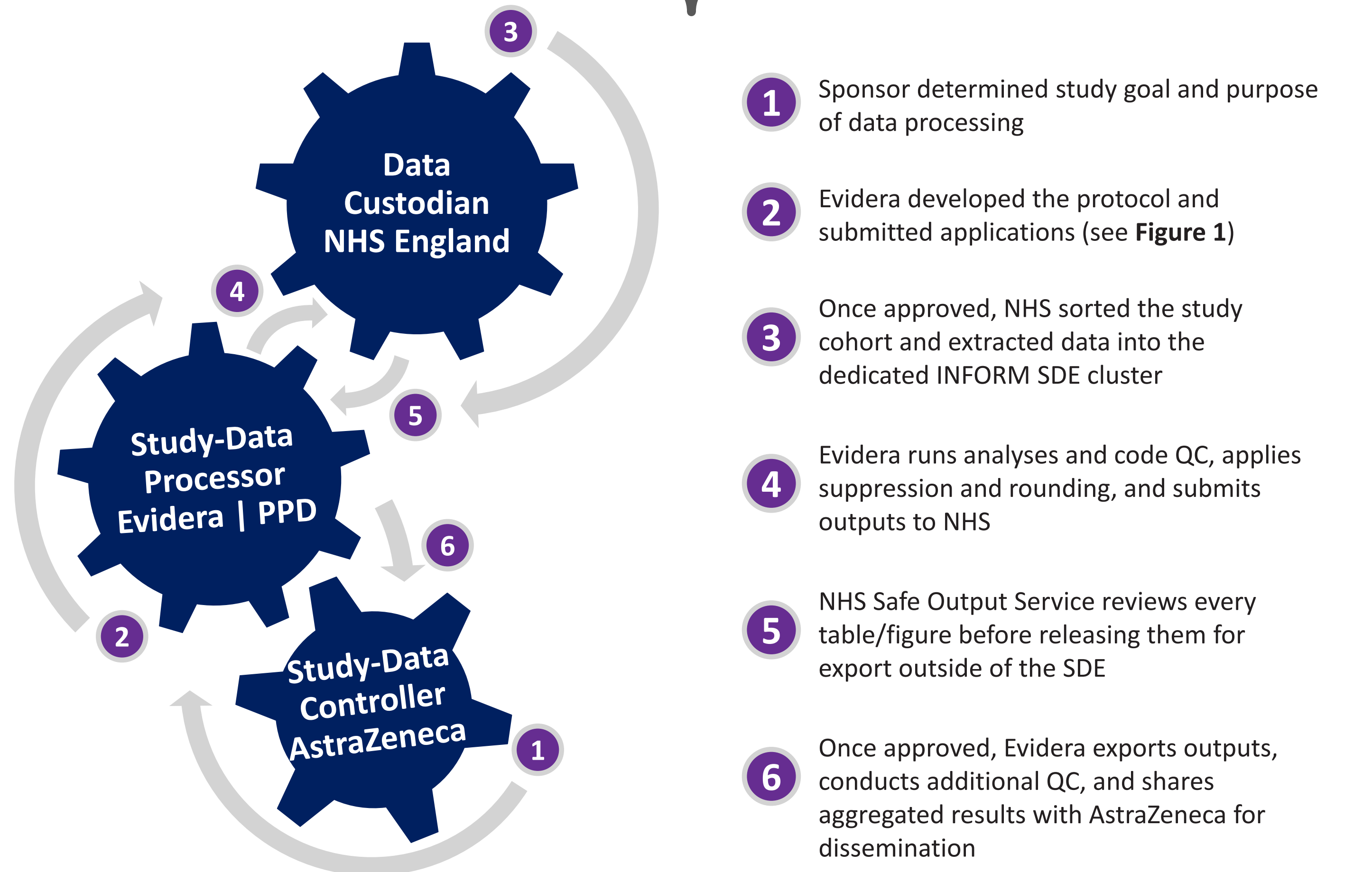
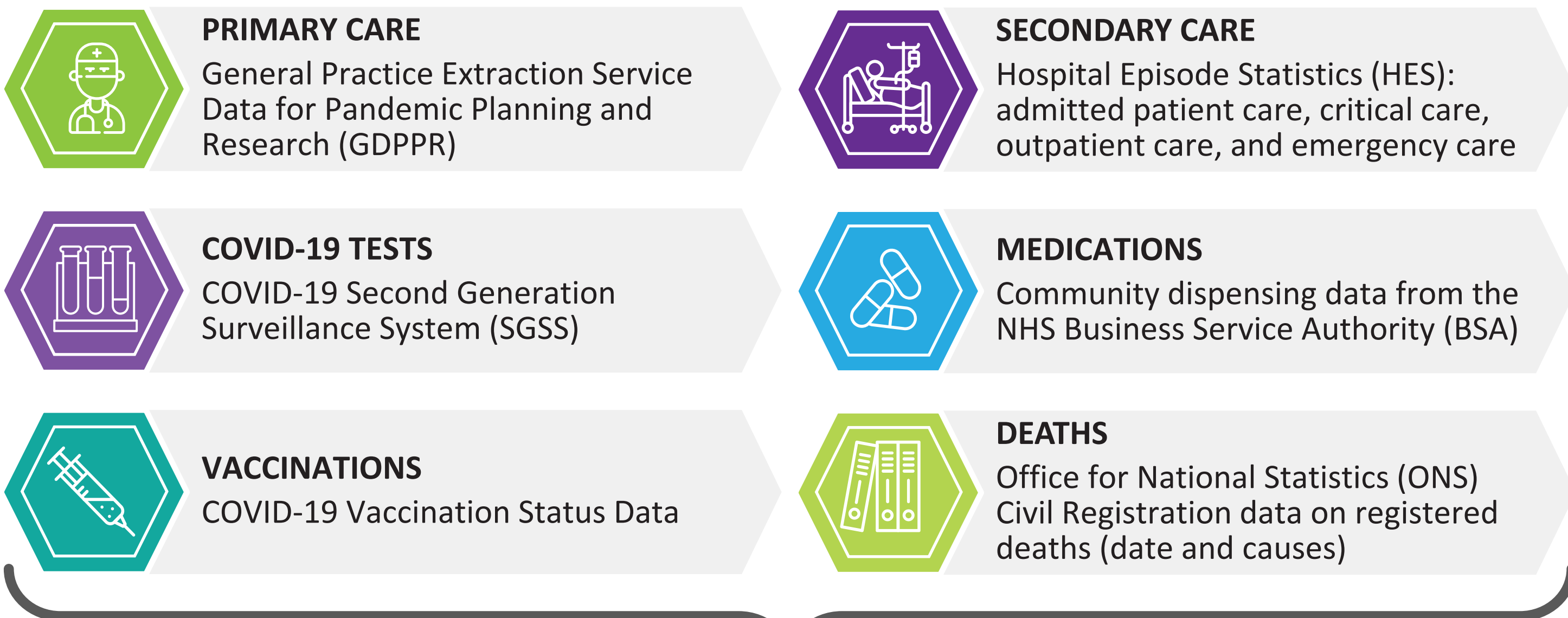
References

- Evans RA, Dube S, Lu Y, et al. Impact of COVID-19 on immunocompromised populations during the Omicron era: insights from the observational population-based INFORM study. *Lancet Reg Health Eur.* 2023;35:100747.

Data Access for Analyses

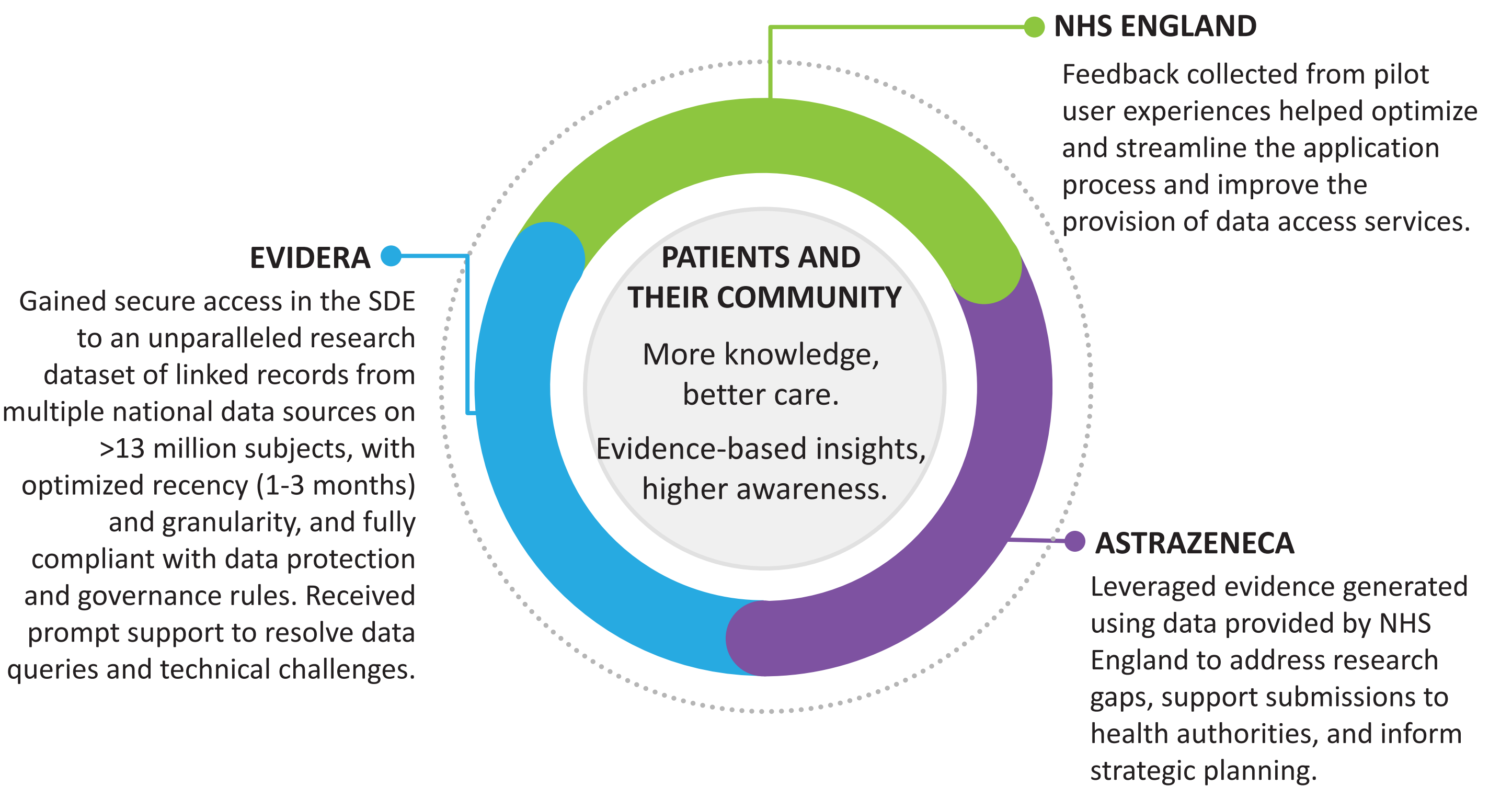
- Figure 3 provides an overview of data accessed within the SDE and the process for data management, analysis, quality control, compliance checks, and export of results for dissemination.

Figure 3. Overview of Data Sources and Data Access Model



Abbreviations: NHS = National Health Service; QC = quality control; SDE = secure data environment

Benefits for Each Stakeholder



Abbreviations: NHS = National Health Service; SDE = secure data environment

Conclusions

The success of the INFORM study is attributed to the collaboration between various stakeholders, including specialists in science, legal, privacy, information technology, operations, and compliance functions. This unique collaborative experience demonstrated the feasibility of enabling access for the wider research community, generating research evidence that benefits patients and the public without compromising privacy protection. Operational since December 2022, NHS England's SDE continues to expand its technical and service capabilities to enable secure access to health and social care data.

Disclosures/Acknowledgments

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